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'I know I'm not invincible': An interpretative phenomenological analysis of thyroid cancer in young people

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Objective. Thyroid cancer is one of the most common cancers affecting young people and carries an excellent prognosis. Little is known about the psychosocial issues that face young people diagnosed with a treatable cancer. This study explored how young people experienced diagnosis, treatment, and how they made sense of an experience which challenged their views on what it means to have cancer.

Method. Semi-structured interviews were conducted with eight young people diagnosed with either papillary or follicular thyroid cancer, and analysed with interpretative phenomenological analysis (IPA).

Results. Two inter-related aspects of their experience are discussed: (1) the range of feelings and emotions experienced including feeling disregarded, vulnerability, shock and isolation; (2) how they made sense of and ascribed meaning to their experience in the light of the unique nature of their cancer. A thread running throughout the findings highlights that this was a disruptive biographical experience.

Conclusions. Young people experienced a loss of youthful immunity which contrasted with a sense of growth and shift in life perspective. Having a highly treatable cancer was helpful in aiding them to reframe their situation positively but at the same time left them feeling dismissed over a lack of recognition that they had cancer. The young peoples' experiences point to a need for increased understanding of this rare cancer, more effective communication from health care professionals and a greater understanding of the experiential impact of this disease on young people. Suggestions to improve the service provision to this patient group are provided.

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Statement of contribution

What is already known on this subject?

- Differentiated thyroid cancer has an excellent prognosis.
- Quality of life of thyroid cancer has marginally been explored in the literature.
- Little is known on the support needs of young people diagnosed with thyroid cancer.

What does this study add?

- Increased understanding of how young people make sense and cope with thyroid cancer despite the lack of support resources.
- Addressing illness perceptions through improved information support may aid coping and adjustment.
- Insight into the needs of young people diagnosed with thyroid cancer and recommendations on service improvements.

Thyroid cancer is the most common endocrine malignancy that can affect young people (Ying, Huh, Bottomley, Evans, & Waguespack, 2009). Nevertheless, it is a fairly rare and unknown type of cancer. Each year, there are about 3,404 new cases in the United Kingdom with it being more common in women than men. In the United Kingdom, thyroid cancer is the 16th most common cancer in females and 19th in males, and since the early 1990s, incidence rates have more than doubled (139% increase). Thyroid cancer occurs across the lifespan and increases with age in both sexes (Cancer Research UK, 2014). However, among adult cancers, thyroid cancer is most prevalent in young people (American Cancer Society, 2017).

The thyroid gland is the biggest gland in the neck, located at the base of the throat, and absorbs iodine from the diet. It produces thyroid hormones, principally thyroxine (T₄) and triiodothyronine (T₃). These hormones affect heart rate, cholesterol level, body weight, energy level, muscle strength, skin condition, vision, menstrual regularity, and mental state among a host of other conditions (Wolfe, 2003). It is an important gland because every cell in the body depends on thyroid hormones for regulation of its metabolism.

The exact cause is unknown, but radiation is considered a main risk factor. Evidence for this link comes from the Chernobyl nuclear power plant accident, where thyroid cancer rose several hundred times in children living in the region of the failed plant (BTA & RCP, 2007). In terms of the higher incidence in females, it has been suggested that puberty, pregnancy, and menstrual cycles might subject the gland to increases in cell replication (Correa & Chen, 1995).

There are four main types of thyroid cancer. They range from being highly treatable, papillary (the most common) and follicular, to more aggressive, medullary and anaplastic (much rarer) (Cancer Research UK, 2013). Papillary thyroid cancer and follicular thyroid cancer (or a mixture of the two) are often referred to together as differentiated thyroid cancer because they arise from thyroid follicular epithelial cells (Dal Maso, Bosetti, La Vecchia, & Franceschi, 2009). Differentiated thyroid cancer is the most common thyroid cancer worldwide and accounts for more than 90% of thyroid cancers and are generally characterized by slow growth and low mortality (Kitamura *et al.*, 1999). The overall five-year survival rate for patients younger than 40 years is greater than 99% (Ying *et al.*, 2009).

Standard treatment for differentiated thyroid cancer involves surgery. A hemithyroidectomy is performed if the tumour is contained and further treatment is not required. More commonly, surgery involves a total thyroidectomy (with or without lymphadenectomy) which often results in a 2- to 2.5-inch scar at the front of the neck, often followed by

radioactive iodine treatment (RAI) that targets only thyroid cells and does not affect the rest of the body. A total thyroidectomy requires lifelong thyroid replacement therapy (e.g., thyroxine) and follow-up due to the disease having a long natural history, a likely late recurrence, and late side effects of RAI treatment, such as leukaemia or secondary tumours.

Research in the field of thyroid cancer is dominated by the medical aspects of the disease including issues in surgery (e.g., Lennard, 1996) and treatment (e.g., Coelho, Carvalho, & Vaisman, 2007). Only a few studies have investigated quality of life in thyroid cancer identifying a range of physical and psychological effects including voice difficulties, fatigue, weight gain, insomnia, anxiety, depression, skin dryness, and loss of libido (e.g., Almeida, Vartanian, & Kowalski, 2009; Crevenna *et al.*, 2003; Dagan *et al.*, 2004; Giusti *et al.*, 2005; Hoftijzer *et al.*, 2008; Husson *et al.*, 2011; Mendoza *et al.*, 2004; Sawka *et al.*, 2009; Schultz, Stava, & Vassilopoulou-sellin, 2003; Tagay *et al.*, 2006; Tan, Nan, Thumboo, Sundram, & Tan, 2007). Research into testicular cancer which is also a rare and common cancer in the younger male population and is highly treatable if caught early (Testicular Cancer Society, 2017) has shown quality of life to be impacted following the cancer diagnosis. Fear of recurrence (also positively correlated to mental distress, chronic fatigue, and anxiety) (Fossa, Dahl, & Loge, 2003; Skaali *et al.*, 2009), fertility concerns, to non-disclosure of the illness (Saab, Nouredine, Abu-Saad Huijjer, & Dejong, 2014), as well as a need for further written or online information about their condition and side effects of treatment (Brand, Williams, & Braybrooke, 2015) have been found. Misdiagnosis and waiting times for further investigation have also been reported (Chapple, Ziebland, & McPherson, 2004). Interestingly, Chapple *et al.* (2004) found that the media, or seeing leaflets at their GP's, or knowing others with the cancer aided most men to quickly respond to their symptoms. However, the same cannot be said for thyroid cancer which lacks media attention (e.g., cancer charities campaign's which often include celebrities) and is less known in the public domain or currently present on lived experience websites (e.g., healthtalk.org).

To date, little is known about the lived experience of the impact and adjustment to the diagnosis of this rare and treatable cancer as well as how the young people feel about treatment which involves lifelong tablet intake, regular hospital appointments, blood tests, and side effects such as scarring. This study sought to provide a detailed understanding of the issues faced by young people with thyroid cancer and to examine how they ascribed meaning to their experiences. Of particular interest was developing a better understanding of how the young people made sense of having a treatable and rare cancer in the light of the knowledge they had about other well-known cancers and mortality rates.

Method

Ethical approval was obtained from the Oxford Research Ethics Committee and the NHS Research and Development Department in Oxford. Study approval was also gained following an in-depth review from a Cancer Patient Partnership Group in Buckinghamshire.

Participants

Ten patients were invited to participate, with eight taking part (six women and two men). This number was influenced by recruitment difficulties due to low incidence rates, especially in males which is representative of the disease being two to three times more

prevalent in women (NHS Choices, 2016). All participants were White British, with no dependents, and aged between 19 and 34 years. The majority had undergone a total thyroidectomy at their local hospital and had been referred for RAI treatment. All were receiving follow-up care at the thyroid clinic in Oxford (see Table 1 for the participants' profiles).

Eligibility criteria included being aged between 16 and 35, diagnosed and treated for papillary thyroid cancer or follicular thyroid cancer in the last five years, and being at least 6 months post-diagnosis. Due to the low incidence of thyroid cancer, these criteria provided more opportunity for recruiting a suitable number of participants. Papillary thyroid cancer and follicular thyroid cancer were chosen due to both being highly treatable and having a similar prognosis. The cancer patient partnership group and health care professionals involved considered 6 months post-diagnosis a suitable time for participants to be interviewed.

Recruitment

Purposive sampling was used to recruit participants from an established cancer clinic that provides long-term follow-up. Potential participants were identified by the endocrinologists and oncologist involved in the study by review of clinic lists and medical records. Interested participants were introduced to the first author to discuss the study further and provided with the patient information sheet. Contact details and availability were exchanged and the interview date, time, and location confirmed at a later date.

Interviews

Semi-structured interviews were face-to-face, audio-recorded, and conducted by the first author in private consultation rooms at the hospital, with two at a university. Informed consent was obtained and an interview schedule guided the course of the interviews whilst remaining alert to issues that participants raised themselves. Topics included the following: diagnosis and treatment; experience with health care professionals; identity; coping; and views on cancer. The interviews ranged from 1 to 1.5 hr. The audio-recorded interviews were transcribed verbatim. During transcription, pseudonyms were assigned and identifying information removed.

Analysis

The study employed interpretative phenomenological analysis (IPA) because of its dual emphasis on the importance of describing and interpreting the personal meaning of a particular experience of major significance (Smith, Larkin, & Flowers, 2009). The first author led the analysis following principles for IPA (Smith *et al.*, 2009). In brief, each interview was read and listened to on multiple occasions to gain a holistic sense of the participant's account. Notes on anything that appeared significant or of interest were made and then transformed into more specific themes or phrases which called upon psychological concepts and abstractions. Thematic labels were assigned to capture what was most salient for the participant, and these were jotted down in a notebook alongside illustrative material with separate dividers for each participant. The thematic labels for each participant were added to a Microsoft Excel spreadsheet and organized by cutting and pasting electronically, to review connections and establish interrelationships across the group. Following IPA's cyclical nature, connections between main themes and

Table 1. Profile of participants

Pseudonym	Sex	Age at diagnosis	Age at interview	Marital status	Type of thyroid cancer	Treatment	Number of RAI treatments	Attended the Oxford Hospital for
Elise	Female	19	23	Relationship	Papillary	TT, RAI	1	TCC
Kim	Female	17	19	Single	Follicular	TT, RAI	1	TT, RAI, TCC
Chloe	Female	20	25	Single	Papillary	TT, RAI	1	TT, RAI, TCC
Karen	Female	23	23	Relationship	Follicular	TT, RAI	1	RAI, TCC
Julia	Female	28	29	Relationship	Follicular	TT, RAI	1	RAI, TCC
Sophia	Female	26	30	Single	Follicular	PT	0	PT, TCC
Brian	Male	32	34	Single	Papillary	TT, RAI	4	RAI, TCC
Mark	Male	31	34	Relationship	Papillary	TT, RAI	1	RAI, TCC

Note. PT = partial thyroidectomy; RAI = radioactive iodine ablation; TCC = Thyroid Cancer Clinic; TT = total thyroidectomy.

constituent themes were maintained, modified, discarded, or reintroduced. A master list was produced to record each superordinate theme and the themes of which it was comprised.

Quality control and reflexivity

Preliminary findings were presented and discussed with an IPA research group that was run by the second author. Coded transcripts and integration were reviewed by an independent researcher, the third author. Additionally, the first author kept a reflexive diary during the analysis. Reflecting on personal reactions to the narratives often involved revisiting the data and diary entries at several points during the process. Final themes were reviewed by all the authors.

The researchers' location

A varied research team aids to advance the transference of knowledge across disciplines, whilst ensuring all ethical considerations are taken into account. The first author is a chartered and registered health psychologist, and a qualitative researcher with experience working with oncology patients. The second author is a university-based qualitative researcher with expertise in phenomenological approaches, predominantly IPA. The third author's background is in health psychology and mixed methods. The fourth and sixth authors (consultant endocrinologists) and fifth author (a consultant oncologist) all have expertise in diagnosing and treating patients with thyroid cancer.

The analytic narrative

Here, we discuss the key thematic features of the young peoples' experience. Two superordinate themes were derived. The first theme, 'feelings of disregard, vulnerability, shock, and isolation', describes the emotional impact of being diagnosed and treated for thyroid cancer, and is comprised of two subthemes, 'feeling disregarded' and 'isolation'. Whilst the second, 'making sense of and coping with a relatively rare form of cancer', examines how the young people make sense of this experience through the subthemes 'the best cancer to have?' and 'benefit finding'. Throughout this section, we emphasize how this was a disruptive biographical experience which challenged illness perceptions and what it means to be young. In particular, the themes address how having a rare and treatable cancer shapes and influences relations with health care professionals, family, and friends as well as one's sense of self.

Feelings of disregard, vulnerability, shock, and isolation

This theme describes the participants' experiences of feeling disregarded by health care professionals. Difficulties in obtaining a diagnosis and the way the diagnosis was communicated gave rise to a sense of vulnerability and shock. The apparent lack of support from having a treatable cancer also left individuals feeling isolated.

Feeling disregarded

All participants had a neck lump which was described as having 'just appeared'. They had no other symptoms and did not feel ill, and reactions to the lump were mixed. Some of the young people immediately associated the lump with cancer exemplified by Chloe:

I immediately thought cancer 'cause I think that's quite a natural thing that people feel lumps. . .but I didn't really. . .think it could definitely be that.

Chloe's response reflects the omnipresent nature of cancer and how making an immediate association between cancer and a lump is a 'natural' and normal thing to do. At the same time, she dismisses the idea; this might be because of her youth or it might be that she is drawing on 'really old people got cancer' discourses. In contrast, there was a lack of concern from other young people who ignored their lump initially until they noticed it 'growing' or associated it with past health conditions:

I'd always had like tonsillitis, you know, glands were up. . .I didn't really think anything of it.
(Sophia)

It is noteworthy that when the young people visited their GP that their mixed reactions of unconcern versus concern were reflected in the GPs' responses. Most felt that they were not taken seriously and described delays and difficulties, an experience portrayed as 'hit and miss':

I'd a lump on the side of my neck for. . .three years. . .my GP at the time wasn't particularly interested. . .it was only when I moved house. . .went to see him [the new GP] about something else and he wasn't really interested in what I went to see him about and he said "tell me about your neck, not very happy with it." (Julia)

Elise described a similar experience, seeing three different GPs until she was referred:

Went to the doctors two weeks before. . .[travelling] and they said. . .probably nothing to worry about. . .if it doesn't go down in 4-6 weeks then come back. . .I said. . .I'll have to go and see a GP [abroad] so that's what I did 'cause it didn't go down. . .Again they said the same thing to me but I said that is why I am coming back. . .so I thought that wasn't very good so I went to another GP.

In this case, Elise took decisive action by finding another GP but experiences like this erode trust in health care professionals and increase feelings of vulnerability; the young people felt that their lump was trivialized and dismissed only to be told they had cancer at a later date.

Unsurprisingly, a diagnosis of thyroid cancer was received with shock as well as disbelief, not least because cancer was perceived as an illness that happened to older people (this perception is explored in the final theme). The young people were relieved that it was highly treatable, but they felt that this fact led to a disregard and playing down of the impact of diagnosis. An extreme example of this is Brian who was told whilst in the middle of a procedure:

The bad news came from the guy that did the fine needle. . .I was laid there with this metal thing in my neck. . .I thought ok.

Many of the young people expressed frustration at the way in which the diagnosis was communicated which they believed limited their understanding of what they were being told:

I had cancer but it's not the sort of cancer that kills you. . .they were just using words like, "yeah there's like a five per cent mortality rate with this." (Karen)

The doctor said papillary thyroid carcinoma. . .I was sort of looking around the room at everyone saying somebody fill me in. (Elise)

Although most of the young people said they were given the opportunity to ask questions, they needed time to digest the news and would have preferred to have seen the consultants again, but never got the chance.

Isolation

The variability in the young peoples' emotional experiences is seen during the treatment process as well, in terms of their actions and responses to their dealings with those involved in their treatment. For example, Mark retreated, observing wryly that he had the 'ostrich syndrome' and was willing to 'let the experts do what they have to do'. Julia, however, felt frustrated at what she saw as limited information and she described feeling in limbo whilst undergoing RAI treatment:

It's just the unknown. You just have no idea of what's going to happen. . .or what kind of room it's going to be.

Most reacted by becoming self-reliant and sought information via the Internet or books. However, the information found often caused more worry:

I didn't know if it was the most common one. . .or the most serious one. (Julia)

This also caused difficulties when explaining the diagnosis to others which further isolated them. Many stated that they wished they had been given a detailed information guide that included material on the thyroid, the different types of thyroid cancer, the treatment process, the potential risks of RAI, and side effects of the treatment. Other suggestions included being made aware of the different treatment scenarios, time frames/map of progress, and having case studies of other patient's experiences and outcomes.

All the young people said that they had not been given information about support groups and/or counselling which consolidated their sense of being disregarded and discounted throughout the process. Most had not met anyone in the 'same boat' and needed to hear success stories and speak to others with thyroid cancer who could understand what they were going through. Similarly, some reported needing an outlet like counselling as they found it 'draining' to remain upbeat to supportive family and friends. Their general feeling was of an indifferent attitude on the part of the health care professionals because the cancer was treatable:

I said "please is there somebody I could talk to?" and he said. . ."I don't know if it is serious enough." (Karen)

Clearly, the 'hit and miss' experience of GPs responses is echoed at the time of diagnosis and throughout treatment. From the perspective of some health care professionals, having a treatable cancer seems to minimize understanding of the impact of a cancer diagnosis. In particular, the young peoples' confidence in their GP was impacted as they considered them less knowledgeable in managing thyroid cancer and related medical issues post-treatment.

Finally, due to the nature of the RAI treatment, many of the young people felt isolated, feeling different from other cancer patients. Treatment was described as having the 'lurgy' and they felt like 'lepers' being segregated. For example, Mark says:

The nurse. . . quickly runs in. . . chucks it down your throat [RAI tablet], runs away and you're left on your own.

Similarly, others felt 'dirty' because they had to wear gloves to touch anything in the isolation room as well as having to shower three times a day to wash off any radiation. They were literally radioactive which rendered them dangerous to other people.

Making sense of and coping with a relatively rare form of cancer

This theme describes the barriers encountered being diagnosed with a treatable cancer, and uncertainty about the future. Highlighted are their coping strategies and a new appreciation for life.

The best cancer to have?

All of the young people struggled to comprehend the nature of thyroid cancer. Negative cancer stereotypes such as old-age, chemotherapy, hair loss, pain, and possible death did not apply to them. Similarly, because it is not known what causes it, they felt confused and muddled trying to work out how they might have contributed to their illness:

I don't smoke. . . there was nothing to point to why I would have it. (Sophia)

I'd understand if it was something I'd done or throat cancer. Obviously, I was a smoker. (Elise)

Having a treatable cancer set them apart from people with other forms of cancer and disrupted perceptions of what it means to be ill. Health care professionals were often quoted as offering variations of, 'If you could choose a cancer this is the one to have' which was helpful for some of the young people especially in terms of helping others understand. However, this sort of reassurance prevented some from feeling worthy of help:

I wasn't going to be very ill. . . I didn't deserve all the resources and the attention that other people deserved. (Karen)

Brian goes on to highlight the tensions involved in being a 'person with cancer' but not fitting cultural representations and beliefs:

I never felt ill. . . I feel like a bit of a sham.

Brian's shift from the past to the present tense suggests that he *still* feels a sham, and that in some sense, having a treatable cancer and not feeling ill renders him fraudulent in the eyes of others.

Relatedly, although the majority expressed a wish to attend a support group if one had been available, it was thought as 'self-indulgent'.

In sum, the young peoples' responses to having an unfamiliar illness which did not fit with prevailing cancer stereotypes made them cautious about how to disclose their diagnosis and who they should tell and where possible, they avoided using the word cancer. It seems that there is considerable mismatch between previously held mental representations and beliefs of what it means to have cancer and their lived experience of having thyroid cancer.

The diagnosis, treatment, and knowledge that they faced a lifelong maintenance regime were a disruptive biographical experience for these young people. For example, the majority were unused to taking regular medication and found it restrictive in contrast to their perceptions of a previously unhindered life.

I used to be quite, oh, I'm going for a sleepover. . . which I can't do unless I have all my tablets.
(Kim)

I was hoping to maybe emigrate. . . it's just transferring everything over. . . having to obviously see new people. . . getting the medication from elsewhere. (Mark)

There is a hint of resentment in Kim's statement whilst Mark seems daunted at the prospect. Although these feelings are likely to diminish over time as taking regular medication becomes a daily routine, there is a clear sense of restriction in what Kim and Mark say indicating that a process of adjustment is needed.

The young people believed that life possibilities and choices had narrowed (e.g., certain professions) and that they had lost the carefree attitudes embodied in youth:

I used to be very outgoing. . . bungee jumping. . . to I had a fearful stage of if I've got over cancer. . . I don't want to put myself in a position where I could have my life taken. (Sophia)

Although knowing she has a highly treatable cancer, Sophia seems to be implying that she has had a brush with death which has changed her; previously acceptable risky behaviours are no longer an option because they are now tinged with fears of mortality.

All of the young people felt uncertainty about the future, and some feared the cancer recurring or developing other forms of the disease. For instance, Chloe said, 'Often people do get a cancer later in life and I just wonder if I am more likely than others'. Also, there were fears over infertility and disclosing the illness and treatment to future partners:

I've kinda got it in my head that people. . . they think. . . if you've had cancer or something maybe there's a weakness in your genes. (Brian)

For these young people, their belief in youthful immunity had been challenged exemplified by Julia:

I know I'm not invincible. . . it does make you feel a bit more that life could end tomorrow.

Youth is perceived as a form of superpower and even though these young people knew they had a 'good cancer', it did not stop them thinking and feeling that this power had been stripped from them making them aware of the frailty of life.

Benefit finding

Although having thyroid cancer was a distressing and disrupting life event, many of the young people reflected on how their experience was, at least in part, one of positive change and growth. Importantly, negative stereotypes of cancer were challenged alongside increased awareness of the various forms of cancer and survival rates:

You know it's still a scary word, but your view of it becomes a little bit more educated. (Sophia)

Over time, they came to see themselves as 'lucky' and fortunate that they did not have to undergo chemotherapy and that compared to others they were relatively pain free:

This guy was just sort of screaming through the night, it made me feel sort of grateful that I wasn't really going through that level of suffering. (Brian)

This positive shift in perspective is emphasized in how they came to view their postoperative scar. Initially, the young people experienced a change in their social situations with regard to the scar. Most experienced uncomfortable reactions from others. Karen described not being prepared for others remarks:

Somebody who I hadn't seen for a while... said "oh my god you look like you've just hung yourself."

For most, this resulted in some covering up their scars or avoiding social engagements altogether. However, these feelings were short term, as the scar for most eventually disappeared to a faint line shortly after the operation. Although some of the young people were happier than others with the outcome, all expressed a new appreciation and acceptance of the outcome. For some, the scar had become an affirmative sign of what they had endured:

I've got something to prove what I've been through and it's like a war wound. (Karen)

It might be that the visible sign of a scar is an important validation that they had indeed had cancer which might have helped to redress some of the disregard they had experienced.

Finally, there was evidence of the majority of these young people reflecting and evaluating their experience and an ability to frame it in terms of personal growth exemplified by Chloe:

It just enriches all your different experiences like just not going along on par, having a bit of a kinda dip down but recovering from it makes you appreciate it when you're a bit higher up but so I think it's just added to my history and my experience.

Their youth and the fact that they had a highly treatable cancer are likely to be strong determinants of this positive thinking, but it also speaks to the strong narrative and temporal dimensions of our lived experiences.

Discussion

The research explored the processes of reaction and adjustment among a group of young people diagnosed with thyroid cancer. The analysis highlights the range of emotions and

feelings the participants experienced as well as how they made sense of having a rare cancer.

This exploratory study adds to the small body of literature about this fairly unknown form of cancer among young people. In this section, we examine the young peoples' experiences in the light of what is already known in the extant literature as well as a brief consideration of how the study makes a contribution to ideas of illness perception. Sample considerations, contributions, and implications are also reviewed.

The young people experienced feelings of vulnerability and held perceptions of disregard and dismissal concerning health care relationships. Often, these were a response to what they saw as a trivialization of their symptoms from their GPs which is similar to Berry's (2011) study where participants visited their GP at least four times before receiving a diagnosis, despite presenting with at least two symptoms associated with cancer. Fitzpatrick and Vangelisti (2001) suggest that stereotypes of who suffers from cancer influence GPs' interactions and communication with patients seems relevant here. Unfamiliarity with thyroid cancer given its low incidence rates coupled with age stereotypes of who gets cancer means that when GPs are confronted with otherwise healthy young people, they might come across as indifferent and/or fail to take appropriate action. Moreover, the young people described the process of diagnosis as negative and many were dissatisfied and frustrated with the focus on statistics and use of medical jargon to provide information. Likewise, Sawka *et al.* (2009) found clear evidence of a desire for 'plain-language information'.

A sense of isolation characterized the entire experience for these young people; not only were they physically isolated from people with other types of cancer because of the nature of the RAI treatment, they *felt* isolated because of their particular cancer (e.g., not relating to other cancers, not meeting other young people with thyroid cancer, and the lack of information support and access to support services). Similar findings were found with Easley, Miedema, and Robinson (2013) in their study with young people with thyroid cancer. They argue that patients with thyroid cancer require significant emotional and psychological support. The current study found there was a need to identify with others who had experienced thyroid cancer. Other research has demonstrated that peer support groups provide shared understanding, positive role models, and information regarding coping, which would not be available from friends and family (e.g., Clarke, McCorry, & Dempster, 2011; Coyne & Borbasi, 2007; Mathews, 2000). In the current study, dealing with the lack of information, the Internet was a key resource. However, barriers were often encountered due to the lack of information, that is what type of thyroid cancer they had. This accords with Sawka *et al.* (2009) who noted that disclosure is valued by patients with thyroid cancer. They found that whilst the Internet was considered accessible, the information available was not always relevant to their thyroid cancer or life situation. In sum, the findings highlight the need to improve information about the bio-psycho-social aspects of thyroid cancer and support services. These improvements would be beneficial in reducing the isolation experienced for this population.

As is commonly found in reactions to traumatic events, the participant's sense of self and their own perceptions of the world were shaken by their diagnosis. The shock at the cancer diagnosis appeared to be related to age and expectations of being immune from cancer. Many referred to stereotypes of cancer (e.g., elderly, chemotherapy, pain, and death) which accords with long-standing observations that a sense of being invincible is widely experienced by young people (e.g., Allison & Campbell, 2009; Miedema, Hamilton, & Easley, 2007; Wickman, Anderson, & Smith Greenberg, 2008). In all instances, the invincibility of youth was confronted by the reality of a serious health issue.

The young people revealed a loss of carefree attitudes and new future concerns (i.e., recurrence, fertility, and osteoporosis). Similarly, women with early-stage breast cancer expressed fears about disease recurrence and uncertainty about the future (Allen, Savadatti, & Gurmankin Levy, 2009; Coyne & Borbasi, 2007). Many participants in this study felt that thyroid cancer had removed choices, especially in the social environment (e.g., certain professions) due to the impact of the treatment and their reliance on medication to maintain normal hormonal health. Whilst thyroid cancer is framed in a positive way as 'the best cancer', this should not detract from the fact that it is a cancer (Rosenthal, 2002; Sawka *et al.*, 2009). Being told they had acquired 'the best cancer' aided participants in coping and informing others but at the same time prevented some from grieving their diagnosis, and not feeling entitled to support, a finding reported elsewhere (Easley *et al.*, 2013).

Whilst the thyroid cancer diagnosis and treatment were distressing and disruptive, most reported personal growth as a consequence. The relationship between benefit finding and adjustment to cancer is often moderated by time (Helgeson, Reynolds, & Tomich, 2006). In support, participants in the current study seemed to evolve and change their perceptions with time and completion of treatment. An unexpected finding was the shift that occurred in perceptions of the scar, which for many became a positive symbol representing their experience. Baile and Scott (1994) state that among all the anatomical sites of cancer, those of the head and neck carry the highest psychiatric morbidity. In the current study, the initial visible neck scars resulted in embarrassment and often a loss of confidence in social situations and for some concealing their scars. The shift in perception may have been aided by the fact that for many, the scar became unnoticeable and/or may have been a way for some of the young people to take charge of what they had been through against feeling disregarded as well as experiencing negative comments and stares from others. However, looking beyond thyroid cancer, the literature suggests that this is not a too surprising outcome and people show both an appreciation of scars and covering them up. For example, Slatman, Halsema, and Meershoek (2016) found women coming to terms with their scarred body after breast surgery were both an individual and social matter. In particular, it was found that women who concealed their scar did not want to inconvenience others whilst it was suggested that those who displayed their scar impacted on their own experience of it (e.g., personally helped them get used to the scar). Wallace, Harcourt, and Rumsey (2007) study on adolescents' experiences of adjustment to appearance resulting from meningococcal septicaemia found that over time, participants accepted their altered appearance. When offered to improve their scarring surgically, many declined to do so suggesting acceptance of their new appearance. The authors support the move from a pessimistic perspective on 'defeat' and 'limitations' towards a more positive outlook that 'enhances resilience'.

The present study suggests that participants assigning different values to their lives post-diagnosis, benefit finding may be an important means for coping. Similarly, Costa and Pakenham (2012) found benefit finding was strongly associated with wisdom, spiritual well-being, and lifestyle changes. Reframing the situation in a positive light helped participants continue coping with treatment and post-diagnosis. However, participants often did this through comparison to other cancers which emphasized the uniqueness of thyroid cancer (Festinger, 1954). The benefit of downward social comparison as a way of protecting self-concept is widely documented (Helgeson & Taylor, 1993; Miedema *et al.*, 2007; Taylor & Lobel, 1989), and helpful in enhancing self-esteem among stigmatized groups (Crocker & Major, 1989). However, downward comparisons could be detrimental,

as it increases the availability of hypothetical worse worlds, which individuals may come to inhabit (Buunk, Collins, Taylor, Vanyperen, & Dakof, 1990). For these participants, the presence of a treatable cancer was an interesting dynamic, as a worse world was often conceived as undergoing chemotherapy. Most participants had not met others with thyroid cancer, and therefore, upward social comparisons were limited. This study indicates that benefit finding may help restore meaning to the participant's lives and can therefore facilitate adjustment to the experience of thyroid cancer.

The current study highlights that young people's perceptions of cancer over time plays a role in making sense of dealing with a rare cancer. According to the common-sense model (CSM) of illness perceptions (both cognitive and emotional) and coping responses strongly influence outcomes (Leventhal, Brissette, & Leventhal, 2003). Hale, Treharne, and Kitas (2007, p. 904) state that the key construct within the CSM is the idea of illness representation or 'lay' beliefs about illness. These representations integrate with existing schemata, that is the normative guidelines that people hold, enabling them to make sense of the symptoms and guide any coping actions (Hale *et al.*, 2007). Similarly, the participants in the current study often relied on their lay beliefs due to the lack of information on their condition. Applying the findings to the five components of the model aids to explain how perceptions occur and change and adoption of coping behaviours. 1) Identity – participants in the current study were clearly influenced by negative stereotypes of cancer, and death was commonly feared in the initial stages of diagnosis and treatment due to being an unknown cancer and the lack of information they received. They felt forced into a group that they did not identify with. 2) Cause – participants struggled to understand how they had contributed to the illness. 3) Timeline – participants eventually with time perceived themselves from being unlucky to lucky for having a treatable cancer through comparisons with other cancers. 4) Consequences – although seeing their cancer as treatable allowed participants to minimize distress, it also prevented them from getting sufficient support. This was also reinforced by health care professionals. 5) Curability/controllability – despite feeling lucky, many felt that they had lost control of certain aspects of their life, for example certain professions and being reliant on medication from a previous care-free attitude.

Awareness among researchers and health care professionals of the ways in which the attitudes, perceptions, and experience of chronic illnesses might influence, and be influenced by, a patient's interpretation and responses to symptoms is increasingly important in allowing the health care professions to respond more appropriately to patients' needs. Particularly, information and availability of support services need to be improved for this population. In support, Wiener, Cassisi, Paulson, Husson, and Gupta (2017) found that greater information support was associated with more positive illness perceptions and that more positive illness perceptions were associated with less distress in survivors of differentiated thyroid cancer. Addressing illness perceptions early on through tailored interventions such as improved information support, access to other thyroid cancer patients' stories, and improved communication/training with health care professionals may reduce the impact of the diagnosis and contribute to improving coping and adjustment for this population.

Unique research contributions

This study has used IPA to explore young peoples' priorities and perspectives on the ways this unique cancer affects psychosocial adjustment and interactions with the

health services. As such, this research deepens the extant knowledge base regarding the processes and factors distinguishing the young person's experiences, and in doing so, provides guidance for health services delivery in this population. The research provides a unique contribution to the field of bad news. Whilst previous research has found that health care professionals may feel uncomfortable giving someone a devastating diagnosis (Baile & Beale, 2003) and that there needs to be a balance on giving hope without endorsing unrealistic expectations (Brown, Parker, Furber, & Thomas, 2011), these are not issues of particular concern in thyroid cancer due to it being so treatable. The research has highlighted that patients are still receiving a cancer diagnosis that should not be overshadowed with how treatable it is. The study adds to existing literature on benefit finding suggesting that rumination and downward comparisons may lead to benefit finding. Benefit finding was found to help restore meaning and facilitate the thyroid cancer experience. Finally, the apparent benignity of the cancer belies the fact that this patient group had a vital gland removed and that most never feel the same afterwards. They will be reliant on medication throughout life as well as wellness checks to determine hormone levels and examinations to ensure they remain cancer free. The current study therefore challenges stereotypical views of cancer and illness perceptions and highlights the spectrum of experiences within the field of cancer care.

Sample considerations

A particular age group and cancer was specifically targeted for recruitment, and it is possible that participants were those who had reached a stage of acceptance and felt able to talk about their experiences. Individuals who may be struggling to cope with their diagnosis may not be represented here. All participants in this study were White and English speaking, which may limit the applicability of the findings to other populations.

Implications and conclusions

General clinical implications concern the need to facilitate patient understanding of their condition by strengthening the alliance between medical staff and patients. This may include the following specific areas for development:

1. *Information provision.* Information needs to be readily available and appropriate to the individual's needs. A comprehensive care summary and follow-up plan that is clearly and effectively explained would be beneficial to the services.
2. *Communicating with others who have experienced thyroid cancer.* Further exploration into a thyroid cancer support group or web-based support and its benefits requires further consideration.
3. *Emphasis of thyroid cancer to GPs.* The importance of neck lumps, follow-up care and psychosocial aspect of the illness among young people needs to be emphasized to GPs.

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Conflict of interest

All authors declare no conflict of interest.

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